

# **Systems Development for Family Caregiver Support Services**

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## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>21</b>
<b>INTRODUCTION.....</b>	<b>23</b>
Background .....	23
<b>STATE-FUNDED CAREGIVER SUPPORT SERVICES: APPROACHES AND LESSONS LEARNED .....</b>	<b>24</b>
<b>PRINCIPLES TO GUIDE SYSTEMS DEVELOPMENT .....</b>	<b>26</b>
Family Role .....	26
Access.....	26
Coordination.....	27
Comprehensive Services Offering Choice .....	27
Diversity .....	28
Participation.....	28
Respect .....	28
Accountability .....	29
<b>CONCLUSION .....</b>	<b>29</b>
<b>AUTHOR DESCRIPTION .....</b>	<b>30</b>
<b>REFERENCES.....</b>	<b>31</b>

## EXECUTIVE SUMMARY

Caregiving, which is one of the most personal of issues, has now become a major public concern. As the population ages, more and more Americans face the challenges of providing care to loved ones who need help because of chronic illness or disability. Recognizing and supporting family caregivers is a central component of a comprehensive long-term care system. This concept builds on the strong preference of persons who require help with everyday activities to remain at home with their families and in their communities for as long as possible.

This paper provides a framework for discussion on systems development for family caregiver support services by: (1) profiling the major findings of a 15-state survey of state-funded caregiver support programs; (2) providing examples of model programs; (3) highlighting basic principles to guide systems development; and (4) offering practical information on developing systems of support for family and informal caregivers.

Family and informal caregivers are the backbone of our long-term care system. While caregiving affects people in different ways, a body of research over the past twenty years shows common themes: lack of comprehensive, quality and relevant information; financial pressures; legal quandaries; health problems; emotional turmoil; family conflict; and social isolation.

The vast majority of long-term care is provided informally and privately, at no public cost. Often at great sacrifice, families strive to keep a loved one at home, avoiding more costly institutional care. Most caregivers are reluctant to use formal help, continue to provide care with little support, experience adverse consequences to their own physical and mental health, and use formal services only as a last resort.

To date, relatively few states have developed strategies to support and strengthen caregiving families. Those states that have created support services have typically funded them with general revenues. Some states, notably California (with its Caregiver Resource Centers) and Pennsylvania (with its Family Caregiver Support Program) have developed, through state law, separate programs and specific funding and services for family caregivers. Others, like Wisconsin (with its Community Options Program), have integrated caregiver support as part of an array of community-based long-term care services for people with disabilities or frail elders and their family caregivers.

Substantial variations exist in caregiver eligibility from state to state, and in some cases, programs within states. Eligibility criteria typically vary by diagnosis or functional level of impairment, age and income. State programs that focus on caregivers of those with cognitive impairments tend to promote more “family centered” service models. Most state-funded programs make services available to middle income families, often through a sliding fee scale or cost sharing.

State-funded programs also vary in the range and scope of caregiver support services provided. Respite care is the service most typically funded by state governments. Key program components of the most comprehensive state-funded programs include uniform assessment of caregiver needs, flexible package of caregiver services, broad income eligibility, consumer direction, and a range of respite options to help families with diverse and ever-changing caregiving situations.

The goals of systems development should promote seamless services, lead to efficient use of resources, and achieve positive outcomes for caregivers. The following principles are offered to guide systems development of support services for family caregivers:

- 1) *Family Role*: Recognize and support family and informal caregivers as legitimate consumers in everyday activities that surround long-term care.
- 2) *Access*: Offer access to high quality information and services throughout the caregiving process for caregivers of all ages and income levels wherever they live in a state.
- 3) *Coordination*: Coordinate services for caregivers and build on existing infrastructures, rather than develop a patchwork of services that vary from state to state and community to community.
- 4) *Comprehensive Services Offering Choice*: Promote comprehensive caregiver support services that are tailored to the multiple needs of the individual caregiver that change over time.
- 5) *Diversity*: Develop services and service options that address the increasingly diverse and changing population of family caregivers.
- 6) *Participation*: Maximize family involvement in service planning and delivery and ensure that caregivers fully participate in care decisions.
- 7) *Respect*: Respect the needs of the family caregiver and preserve the dignity and autonomy of the care receiver.
- 8) *Accountability*: Build into all caregiver support programs a uniform caregiver assessment process and information system to assure quality of care and caregiver outcomes.

Persons with chronic illness and disabilities need a broad range of information and services over a prolonged period of time. *So do their family caregivers.* The challenge for states in implementing the NFCSP is to ensure that families are recognized and supported as legitimate consumers in long-term care through a cohesive system of caregiver support. Wherever family caregivers live, they should be able to choose from a full array of services and service delivery options that will meet their individual needs, preferences and values.

## INTRODUCTION

Caregiving, which is one of the most personal of issues, has now become a major public concern. As the population ages, more and more Americans face the challenges of providing care to loved ones who need help because of chronic illness or disability. Today, the term “family caregiver” is part of our language and, in a number of states, the designation is used in service delivery terminology. This is due, in part, to the aging of the population, including the baby boomers, and the increased attention to health-related issues in the mass media and on the Internet.

The concept of caregiver support has emerged as a salient public policy issue because, increasingly, many public officials are personally affected by caregiving. Moreover, those who work in the field of aging are also being personally affected by caregiving, either by providing care to older parents, spouses and other relatives and friends, or knowing someone who does.

Recognizing and supporting family caregivers is a central component of a comprehensive long-term care system. This concept builds on the strong consumer preference of persons who require help with everyday activities to remain at home with their families and in their communities for as long as possible. It also builds on the strength of families and helps them cope with the strain of caregiving (Feinberg, 1997).

The purpose of this paper is to provide a framework for discussion on systems development for caregiver support services. The paper profiles the major findings of a 15-state survey of state-funded caregiver support programs, provides examples of model programs, highlights basic principles to guide systems development, and offers practical information on developing systems of support for family and informal caregivers.

## Background

Family and informal caregivers are the backbone of our long-term care system. While caregiving affects people in different ways, a body of research over the past twenty years shows common themes: lack of comprehensive, quality and relevant information; financial pressures; legal quandaries; health problems; emotional turmoil; family conflict; and social isolation. Prolonged caregiving has negative effects on the emotional and physical health of caregivers, even though it is willingly undertaken and often a source of great personal satisfaction (Whitlatch & Noelker, 1996; Zarit et al., 1980).

The vast majority of long-term care is provided informally and privately, at no public cost (Tennstedt, 1999). The economic value of care provided by families, however, is staggering. At an estimated value of \$196 billion nationally (1997 dollars), informal caregiving eclipses home health care (\$32 billion) and nursing home care (\$83 billion) (Arno, Levine & Memmott, 1999). In just four states, family caregivers provide services with an estimated worth of more than \$60 billion: California (\$22.9 billion); Texas (\$13.6 billion); New York (\$13.5 billion); and Florida (\$11.2 billion) (Alzheimer’s Association, 1999).

Some policymakers are concerned that more spending for programs and services will lead families to rely solely on the formal care system. There is little evidence to support this. Family members, primarily wives and adult daughters, are the major providers of long-term care,

providing unpaid care to 64% of adults needing help with daily tasks. About 22% of adults receive care from both unpaid (e.g., family members) and paid (e.g., service providers) sources, while only seven percent of the long-term care population age 18 and older rely exclusively on paid help (Urban Institute, 2000). Eighty-six percent of frail elders with three or more ADL limitations – those at greatest risk of nursing home placement – live with others and receive about 60 hours of informal care a week, supplemented by about 14 hours of paid help (Stone, 2000).

Research has shown that family caregivers continue to provide care for their relatives even if other publicly or privately paid resources are available (Liu et al., 2000; Montgomery and Borgatta, 1989; Tennstedt et al., 1993; Whitlatch et al., 1997). In fact, most caregivers are reluctant to use formal help, continue to provide care with little support, experience adverse consequences to their own physical and mental health, and use formal services only as a last resort (Feinberg, 1997; Gwyther, 1990; Montgomery and Kosloski, 2001).

Often at great sacrifice, families strive to keep a loved one at home, avoiding more costly institutional care. One study estimated that a one-month delay in nursing home placement could save as much as \$1 billion annually in formal health services costs (Leon et al., 1998). While delaying institutionalization is an important policy goal, it also means potentially increasing the emotional, physical and financial toll of family caregivers as they continue to provide care at home and in the community. Therefore, in any long-term care delivery system, programs and services must support and strengthen family and informal caregivers.

Moreover, caregiver support does not stop at institutionalization. Many family caregivers continue to provide help to their relatives who live in assisted living facilities or nursing homes. In one California study, family caregivers who had placed their relative in a nursing home visited their loved one 3 days a week, on average, and continued to provide “hands on” help, particularly with personal and instrumental activities of daily living (Feinberg & Whitlatch, 1995). Still other families engage in long-distance caregiving, arranging for the care of a parent or other relative who may live in another community (Stone, 2000).

## **STATE-FUNDED CAREGIVER SUPPORT SERVICES: APPROACHES AND LESSONS LEARNED**

To date, relatively few states have developed strategies to support and strengthen caregiving families. Those states that have created caregiver support services have typically funded them with general revenues. One of the most striking conclusions from a 1999 survey of 33 state-funded caregiver support programs in 15 states was the broad diversity of approaches states have taken to provide caregiver support programs. The 15 states surveyed varied considerably in the populations to which they direct support services; the eligibility, range and scope of caregiver support services offered; and the amount of funds allocated to support family and informal caregivers (Feinberg & Pilisuk, 1999).

Some states, notably California (with its Caregiver Resource Centers) and Pennsylvania (with its Family Caregiver Support Program), have developed, through state law, separate programs and specific funding and services for family caregivers. Others, like Wisconsin (with its Community Options Program), have integrated caregiver support as part of an array of

community-based long-term care services for people with disabilities or frail elders and their family caregivers.

Substantial variations exist in eligibility from state to state, and, in some cases, programs within states. Eligibility criteria vary by diagnosis or functional level of impairment, age and income. According to Hauptman and Korte (2001), Washington State's new Family Caregiver Support Program, which targets caregivers of adults (age 18+) confronting a wide spectrum of diseases and disabilities, "involves complex challenges related to outreach and service delivery and demands a great system, resource and knowledge capacity on the part of staff and service providers."

Most state-funded programs make services available to middle income families, often through a sliding fee scale or cost sharing mechanism. These families, who are above the eligibility limit for most other public benefit programs yet cannot afford to pay for needed respite and other home and community-based services, are the most at risk for impoverishment (Feinberg & Pilisuk, 1999).

State programs that focus on caregivers of those with cognitive impairments, whether adult-onset (e.g., Alzheimer's disease) or developmental disabilities, tend to promote more "family centered" service models. This is not surprising, since family caregivers of persons with cognitive impairments are more likely than those who care for persons with physical impairments to be involved in everyday care and supervision of their loved one. Some programs target both children and adults, or persons of any age, such as Oregon's Lifespan Respite Care. In Texas, they are bridging the gap between the historically separate aging and developmental disabilities services systems through an innovative program, Support for Individuals with Developmental Disabilities Who Are Aging and Their Family Caregivers (Feinberg & Pilisuk, 1999).

State-funded programs also vary in the range and scope of caregiver support services provided. Respite care is the service most typically funded by state governments. Some states, however, offer a range of caregiver information and support services, including, but not limited to, respite assistance. These states recognize the need for services that directly support the caregiver's well-being, quality of life, coping skills and ability to provide on-going care. The most comprehensive state-funded programs uniformly assess the caregiver's needs and offer a flexible package of caregiver services, including a financial subsidy of some type and a choice of respite options (Feinberg & Pilisuk, 1999). Key program components, many experts agree, include a flexible service package, broad income eligibility, consumer direction and a range of respite options to help families with diverse and ever-changing caregiving situations (Coleman, 2000; Feinberg & Pilisuk, 1999).

In starting a new caregiver support program in a state, the challenge is to allow for a balance of flexibility and accountability: flexibility at the local level to enable innovation, and accountability at the state level to ensure the availability of a range of support services to caregivers across the state (Hauptman & Korte, 2001).

## **PRINCIPLES TO GUIDE SYSTEMS DEVELOPMENT**

Long-term care policy in the U.S. has resulted in a long-term care system that is increasingly fragmented and confusing with a patchwork of services that vary from state to state and community to community (Citizens for Long-Term Care, 2001; Feder, 2000; National Governors' Association, 2000; Stone, 2000). In developing systems of support for family caregivers under the National Family Caregiver Support Program (NFCSP), there is the opportunity to learn from past experience, and design and implement a cohesive and uniform system of care to strengthen family and informal caregivers.

From a consumer perspective, the past 25 years of long-term care delivery have resulted in a “non-system” that creates great confusion, promotes fragmentation, and limits access to people in need, including middle income families in particular. In large part, this is due to the creation of separate funding streams, differing program designs, uncoordinated administrative structures, and wide variability from one community to the next in the way services are delivered. The patchwork long-term care system has resulted in a confusing array of choices that rarely match families' needs (Citizens for Long Term Care, 2001). The goals of systems development should: a) promote seamless support services; b) lead to efficient use of resources; and c) achieve positive outcomes for caregivers. The following principles are offered to guide systems development of support services for family caregivers:

### **Family Role**

Family and informal caregivers should be recognized and supported as legitimate consumers in the everyday activities that surround long-term care. Moreover, the family and informal caregiver should be considered a “client” in need of support services in addition to the care receiver.

The explicit provision of support services for family and informal caregivers is a relatively new concept for many home and community-based programs serving older persons. Who a program designates as its “client” illustrates how programs are designed and services delivered. In some states (e.g., California's Caregiver Resource Centers) the family caregiver is designated as the program's main client, while in other states (e.g., Pennsylvania's Family Caregiver Support Program) both the older person with disability and the family caregiver are considered the clients.

### **Access**

Access to services should be available throughout the caregiving process, and caregivers of all ages and income levels should have access to high quality information and support services wherever they live in a state. Caregivers typically provide care to loved ones over many years. Access to services should be available at onset or initial diagnosis, at crisis points in the caregiver or care receiver's situation, at placement outside the home, even at or following the death of the care receiver (i.e., bereavement services). According to Coleman (2000) several state models of caregiver support address access issues by establishing multi-service caregiver centers throughout a state (California), by allowing families to use funds for the specific services the family needs (Pennsylvania), or by bringing services such as adult day care closer to older people and their families (Georgia).



The notion of caregiver support is a family issue, not just an “aging” issue. Although the current NFCSP limits eligibility to caregivers of persons aged 60 and older, it is recognized that subsequent phases of the program could be strengthened by eliminating the age categorical funding, and folding in caregivers of middle-aged and younger disabled persons in order to develop a comprehensive family caregiver support program.

## **Coordination**

Systems should coordinate services for caregivers and build on existing infrastructures, rather than develop a patchwork of services that vary from state to state and community to community. Some states (e.g., California, Pennsylvania, New Jersey) have a long history of providing comprehensive support to family caregivers and a strong legislative mandate. Other states have more recent state-funded caregiver support programs (e.g., Washington), and still other states have localized, single-service, or disease-specific programs (Coleman, 2000; Feinberg & Pilisuk, 1999; Hauptman & Korte, 2001).

To limit fragmentation and duplication, and reduce “start-up” costs, caregiver support services should be built on existing infrastructures in states where high quality programs already exist. Given the limited resources available under the NFCSP, coordination with existing caregiver support programs are essential to ensure an efficient and effective service delivery system.

## **Comprehensive Services Offering Choice**

Caregiver support services should be comprehensive in scope and tailored to the needs of the individual caregiver. Service delivery systems should coordinate services for caregivers with multiple needs that change over time, providing a seamless array of support services. In contrast to the traditional case management “caseload” model, families come in and out of the system of care over many years, based on their needs and resources, which change over time. For some caregivers, interventions may be intensive initially until the family’s situation stabilizes, and then intermittent as new challenges arise (Feinberg & Ellano, 2000).

While each local (or regional) organization providing caregiver support services should have the flexibility to tailor service delivery to its geographic area, all caregiver support programs should be “consumer friendly” and have a core component of services and service options that provide high quality information, education and support for family and informal caregivers. Family caregivers are often stressed from providing daily care and typically juggle caregiving, employment, and their own family responsibilities. For example, most family caregivers do not have the time to locate and call five community agencies to get information and support. In addition, some long-distance caregivers may live in a different state (or in a different part of a state) than their parent who is in need of care. To ensure a cohesive system of caregiver support, services should be developed with uniform, statewide standards for eligibility and a range of support services that recognize the need for local flexibility to deliver the services. In this way, caregivers can choose from a full array of services and service delivery options that will meet their individual needs, preferences and values.

## **Diversity**

Systems should be developed that address the increasingly culturally diverse and changing population of family caregivers. An increasing ethnically diverse population in many states poses challenges to providing culturally appropriate information and support services to caregivers. The impact of culture affects familial roles in caregiving and varies among ethnic groups (Montgomery & Kosloski, 2001). In Washington State, for example, all AAAs, as part of the proposals for their new state-funded Family Caregiver Support Program (started in October 2000) were required by the state to address the needs of specific ethnic caregivers within their local plans (Hauptman & Korte, 2001). In California -- which has provided specific caregiver support services since 1984-- all Caregiver Resource Centers now have bilingual staff and basic information and educational materials (e.g., brochures, fact sheets) are in key languages.

Promoting services to meet the increasingly diverse needs of working and adult child caregivers will command more attention as the baby boomers age. For example, to address the growing numbers of working caregivers who cannot access services during the work day, virtually all of California's Caregiver Resource Centers now have extended hours until 8:00 pm at night at least one day a week; some centers also offer weekend hours. Aging baby boomers demand more information, choice and options than previous generations to meet their health and long-term care needs and those of their aging parents. The boomer generation is also highly "informed" and skilled in using the Internet to search for information and support. Thus, the growing numbers of adult children caregivers may demand more on-line information and decision support (Kelly, 1997). Particularly for working caregivers, the use of on-line services can greatly assist in providing access to information, education and decision support. Internet-based services, however, are not for everyone. It is but one option increasingly available for family caregivers to access information and support (Feinberg & Ellano, 2000).

## **Participation**

A basic tenet of caregiver support services is to maximize family involvement in service planning and delivery and ensure that caregivers fully participate in care decisions. A core focus of caregiver support services is empowering the family caregiver. Listening to caregivers' needs and taking into account regional concerns and issues of ethnic and cultural diversity are essential components of quality service delivery. Service interventions should enable caregivers to make informed decisions and to learn skills and coping strategies to help them manage home and community-based care (Feinberg & Ellano, 2000). In this way, families retain greater control over their personal lives, are more knowledgeable about service options for their relatives and themselves, are more comfortable with the service system, and are more satisfied when services are actually used (Friss, 1993).

## **Respect**

Respect the needs of the family caregiver and preserve the dignity and autonomy of the care receiver. According to Kane (1995), "In long-term care, both the older person who perceives a need for help and family members who may decide to provide care have decisions to make. One decides whether to accept care, the other whether to give it. Each is influenced by the other, sometimes by explicit advice and sometimes by influencing about what is important to the other" (p. 89). By taking a family systems perspective, both the care receiver and the

caregiver are considered consumers of long-term care services to meet their distinct, but often interrelated, needs.

## **Accountability**

Systems for assuring quality of care and outcomes should be built into all caregiver support programs. To be most effective and efficient, data collection systems to measure outcomes need to be developed before, rather than after programs begin to provide information and support services.

While virtually all state programs utilize some type of an assessment tool to determine the care plan for the person with disabilities, most do not uniformly assess the needs and situation of the family caregiver. That is, few look systematically at the level of distress and caregiver depression, social support, physical health and the caregiver's own service needs (Feinberg & Pilisuk, 1999).

Designing uniform, statewide assessment and information systems should be considered an essential investment to improve quality of care and advance public policy to support and strengthen family caregivers. Client information systems should include but not be limited to: 1) a uniform, in-home psychosocial assessment of caregiver need; 2) reassessment of caregiver need at regular intervals to determine change over time; 3) community resources for the caregiver and care receiver; 4) management information on the numbers of caregivers served, types of services provided, costs and amount of services delivered; and 5) outcomes achieved. Although the development of such information systems can be costly in the short run, investment in information technology can reduce costs in the long run, provide a foundation for the caregiver's plan of care, assess the impact of caregiver support services, improve quality of care, and lay a foundation for new services and policy initiatives.

## **CONCLUSION**

Persons with chronic illness and disabilities need a broad range of information and services over a prolonged period of time. *So do their family and informal caregivers.* The challenge for states in implementing the NFCSP is to ensure that families are recognized and supported as legitimate consumers in long-term care through a cohesive system of caregiver support. Wherever family caregivers live, they should be able to choose from a full array of services and service delivery options that will meet their individual needs, preferences and values.

## AUTHOR DESCRIPTION

Lynn Friss Feinberg is the Deputy Director of the National Center on Caregiving at the San Francisco-based Family Caregiver Alliance (FCA). The center is a national resource of information and technical assistance on caregiving for policymakers, health and service providers, media, and families. In addition, she is co-principal investigator of a research study, funded by The Retirement Research Foundation, to examine decision making and service use in caregiving families over time. Previously, she was FCA's Director of Research and Information Programs where she managed the agency's research, policy development, information clearinghouse and technical assistance programs. She also directed the "Statewide Resources Consultant" contract with the California Department of Mental Health, coordinating the cross-site replication of FCA's model family support program through a statewide system of 11 non-profit Caregiver Resource Centers in California.

Ms. Feinberg has over twenty years experience in the field of aging where she has also served as area agency planner and evaluator, and conducted policy research at the University of California, San Francisco. She is the author or co-author of over 35 publications and has lectured widely on family caregiving, long-term care systems development, and the interface of research and practice. Ms. Feinberg serves on the Board of Directors of the American Society on Aging (ASA), is a Delegate to the National Council on the Aging's (NCOA) National Institute on Community-Based Long-Term Care, an Associate Editor of *The Journal of Mental Health and Aging*, and a member of the American Society on Aging's *Generations* Editorial Board.

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